International Journal of Prisoner Health

A novel care pathway for prisoners with intellectual disability designed through a Delphi process

Journal:	*International Journal of Prisoner Health*
Manuscript ID	IJPH-08-2017-0037.R2
Manuscript Type:	Research Paper
Keywords:	Intellectual Disability, Learning Disability, Prison, Prisoner, Mental Retardation, Ireland

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Abstract

Purpose

Individuals with an intellectual disability form a significant minority in the Irish prison population and worldwide prison populations. There is growing recognition that specialist services for such individuals are in need of development. In this paper, we propose a care pathway for the management of individuals with an intellectual disability who present in prison, based on expert elicitation and consensus.

Methods

A convenience sample of professionals with a special interest in forensic intellectual disabilities were invited to participate in a Delphi exercise. Twelve agreed to participation and 10 subsequently completed the study (83.3%). Expert views were elicited using a semi-structured questionnaire. Content analysis was completed using NVivo 11 software. A care pathway was subsequently proposed, based on the outcomes of the analysis, and circulated to participants for debate and consensus. A consensus was reached on management considerations.

Findings

Ten experts across a range of disciplines with a combined experience of 187 years participated in the study. Current provision of care was seen as limited and geographically variable. The vulnerability of prisoners with intellectual disability was

highlighted. The need for equivalence of care with the community through multidisciplinary input and development of specialist secure and residential placements to facilitate diversion was identified. Consensus was achieved on a proposed care pathway.

Value

This study proposes a care pathway for the assessment and management of prisoners with an intellectual disability and is, therefore, potentially relevant to those interested in this topic internationally who may similarly struggle with the current lack of decision-making tools for this setting. Although written from an Irish perspective, it outlines key considerations for psychiatrists in keeping with international guidance and, therefore, may be generalisable to other jurisdictions.

Keywords

Intellectual Disability

Mental Retardation

Learning Disability

Prison

Prisoner

Ireland

Introduction

A diagnosis of intellectual disability is typically made if an individual meets three criteria: firstly, a score below 2 standard deviations from the mean on a validated test of intelligence; secondly, evidence of significant impairments in adaptive functioning relative to same-age peers; and, finally, a developmental history suggesting onset of difficulties before the age of 18 years. The two major diagnostic systems currently in use are the International Classification of Diseases, 10th Edition (ICD-10) and the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (DSM-5). The prevalence of intellectual disabilities in Ireland is 6.13 per 1,000 population based on National Intellectual Disability Database (NIDD) data from 2015 and using 2011 population census data. The prevalence rate for mild intellectual disability is 1.99 per 1,000, and the rate for moderate, severe or profound intellectual disability is 3.59 per 1,000 (Doyle & Carew, 2016).

The association between intellectual disability (ID) and offending is controversial. Simpson & Hogg (2001) concluded their systematic review of the evidence regarding the association between learning disability and offending by commenting that there is "no clear evidence that the prevalence of offending among people with a learning disability is higher than for the wider population" and that offending amongst those with an IQ less than 50 was rare.

There are little contemporary data in relation to the prevalence of intellectual disability in Irish prisoners (Gulati et al., 2017) and existing data would suggest a higher prevalence than international estimates. A survey of 264 Irish prisoners

(Murphy, Harold, Carey & Mulrooney, 2000) showed a point prevalence of 28.8% for "significant intellectual disabilities" based on a battery of assessments including the Kaufman Brief Intelligence Test, the Wide Range Achievement Test, the Vocabulary sub test from the Weschler Adult Intelligence Scale- Revised and the National Adult Prisoner Survey. However, methodological limitations would suggest potential overestimation based on the lack of standardized tests of functional performance (Gulati et al., 2017; British Psychological Society, 2015). For international comparison, a systematic review evaluating 10 surveys from 4 countries dating between 1966-2004 (Fazel, Xenitidis & Powell, 2008) showed that typically 0.5-1.5% (range 0-2.8%) of prisoners were diagnosed with an intellectual disability. Estimates were likely to be conservative given the limited numbers of studies and substantial heterogeneity and, indeed, a more recent systematic review (Hellenbach et al, 2017) reporting four studies published between 2004-2014 noted a higher prevalence estimate of 7-10% worldwide. Hellenbach et al (2017) stated that none of the studies discussed in their paper applied a full clinical assessment of intellectual disability considering both intellectual and adaptive functioning, in contrast to the 2008 review by Fazel et al., where included studies used the International Classification of Diseases (ICD) or American Association of Mental Retardation (AAMR) criteria.

Irish prisons house approximately 3700 inmates across 14 prisons (Irish Prison Reform Trust, 2016). They have access to primary care seven days a week. The prison General Practitioner, in conjunction with primary care nursing staff, plays a key role in the initial assessment of physical and mental health, and in the initiation of psychiatric referral and/or general hospital referral in the case of a physically unwell individual or when mental illness is suspected. The majority of Irish prisons have

sessional input from a Consultant Forensic Psychiatrist. Service provisions vary from one to three sessions a week in regional prisons to a full time PICLS (Prison In reach and Court Liaison Service) team based at the national remand prison. Similarly, the availability of emergency psychiatric input to a prison is variable geographically. Such geographical variability in access to prison mental healthcare has been described in other developed jurisdictions such as the US (Wilper et al., 2009) and the UK (Offender Health Research Network, 2009). Current screening processes for mental disorder in Irish prisons are variable and where present rely on screening questions for mental illness (Grubin et al., 2002) but not intellectual disabilities. Often, the first time an individual with intellectual disability comes to the attention of prison primary care would be when officers raise concerns regarding vulnerability.

Secure beds in Ireland are limited to the Central Mental Hospital, Dundrum offering High and Medium secure beds for a national catchment area and two Psychiatric Intensive Care Units (Cork and Dublin) offering a lesser secure setting. Only the Central Mental Hospital is designated under the Criminal Law Insanity Act, which limits transfer of remand prisoners through legal provisions. There are no separate specialist secure facilities for learning disabled patients in Ireland save for 10 beds at the Central Mental Hospital in Dublin. The provision of secure beds is therefore both geographically disparate and substantially lower than other Western European countries (Kennedy, 2016). High court orders have been used to access specialist care in the United Kingdom. An expert working group of the Irish College of Psychiatrists postulated a need for at least two 30 bedded specialist units (Leonard et al., 2015). The Irish expert group based this estimate on previously published research that cited the need for 30 specialist beds /500,000 population (Day, 1993)

and an analysis of the needs of "*existing out of state placements*" (i.e., patients who have travelled outside of the Irish jurisdiction in order to receive care due to the lack of appropriate resources within the state). The expert group (Leonard et al., 2015) stated that a *"30-bedded unit has the advantage of critical mass, and value for money… It would provide a tertiary service and specialist in-patient assessment and treatment unit for this population"*.

Patients with an Intellectual Disability needing acute psychiatric care are therefore managed within Acute Psychiatric Units, despite recognition that specialist services are likely to be beneficial (Department of Health and Children, 2006). A national survey of offending behavior amongst intellectually disordered mental health service users in Ireland (Leonard et al., 2015) noted an over-representation of young males, and reducing percentages in terms of severe (45%), moderate (41.3%) and mild (13.7%) degrees of intellectual disability. This study found that the most common offence types were assault followed by indecent exposure, and that amongst the 82 most serious offenders, the vast majority were managed by Intellectual Disability Services or General Adult Psychiatry Services. Care of individuals in the community are either managed by voluntary sector bodies or the Health Service Executive, and this can lead to inconsistencies in provision and issues along interfaces. Advances are being made however through efforts of the Forensic Learning Disability Working Group (Irish College of Psychiatrists, 2005) and the horizon is more positive with the recent appointment of a specialist in Forensic Learning Disabilities at the National Forensic Service and a plan to open ten specialist secure beds in a purpose-built secure facility in Dublin (Mudiwa, 2014).

There is growing international recognition (World Health Organization, 2008) of the need for specialist care provision for those in prison so as to mirror care in the community. In the case of those with disabilities, the principle of non-discrimination is enshrined in the principles contained in the United Nations Convention on the Rights of Persons with Disabilities, which apply to all persons with disabilities, including those facing criminal prosecution and prisoners.

There is limited published guidance specifically advising on care considerations for those with ID in prison. Consequently, there is variation in standards and provision of such care. In this paper, we propose a care pathway to inform such care and outline basic steps that should be considered where an individual in prison is suspected or known to suffer with an intellectual disability. Whilst written from an Irish perspective, these considerations may be generalisable to similar jurisdictions.

Methodology

Ethical approval was obtained from the Research Ethics Committee of the University Hospital Limerick.

A Delphi process (Hasson et al., 2000) was used to elicit expert opinion. This method has advantages over traditional methods in eliciting expert views such as brainstorming sessions and round-table discussion groups to reduce bias from factors such as the presence of a dominant personality, a 'bandwagon effect', polarization of views, and the unwillingness to change an opinion which had been publicly expressed. This technique replaces direct debate by a carefully designed program of

sequential interrogations conducted by questionnaires interspersed with opinion feedback derived by computed consensus from the earlier parts of the program (Brown, 1968).

An email inviting voluntary participation in the study was sent to multidisciplinary professionals including members of an Irish special interest group in forensic intellectual disabilities. Eleven experts (n=11) from Ireland consented to participate. An independent academic psychiatrist (n=1) with expertise in intellectual disabilities from an external jurisdiction (United Kingdom) was separately asked to participate and consented to do so (total n=12).

In round 1, an initial questionnaire **(Table 1)** was agreed by 4 researchers (GG, DM, SQ & CD) and sent electronically to the 12 experts to elicit views with a 6-week response window, and reminder after week 4. Responders were blind to the views of others. Ten responses (83.3%) were received, and all ten respondents completed subsequent rounds of the study (hereafter '*participants*'). Participants included a prison psychiatrist, a forensic learning disability psychiatrist, a consultant in mental health and intellectual disabilities, two consultant psychiatrists in community intellectual disability, a prison chief nursing officer, a forensic psychologist, a probation officer and the external academic psychiatrist with expertise in intellectual disabilities. Participants were based in 6 different Irish counties and had a cumulative experience of 187 years (mean 18.7 years, SD 7.76, range 8-30 years). Six (60%) had completed specialist training in intellectual disabilities.

One researcher (SQ) completed Content Analysis using NVivo 11 software extracting themes and content into a codebook. Content was collated into a proposed algorithm by one researcher (GG) which was circulated to participants for agreement and debate (round 2). Consensus was reached on the algorithm.

Table 1: Initial questionnaire

1. What has been your experience of managing a referral for someone with an intellectual disability (ID) in a prison setting? Was this, for example, a smooth experience, a challenging experience etc?

2. What do you understand the current stages to be, in the assessment of an individual with an ID in an Irish prison setting?

3. In your experience which professionals typically undertake these assessments?

4. To your knowledge, what care is currently available to individuals with an ID in the prison system? Do you feel this is sufficient/appropriate?

5. Which professionals typically deliver such care?

6. What additional roles could be taken on by healthcare professionals in the assessment and care of these individuals? Who may be involved? What would this add?

7. In what circumstances, if any, would you consider treatment in a hospital setting of someone with an ID, currently resident in a prison setting? Have you done this to date? What was the outcome? What problems, if any, did you encounter?

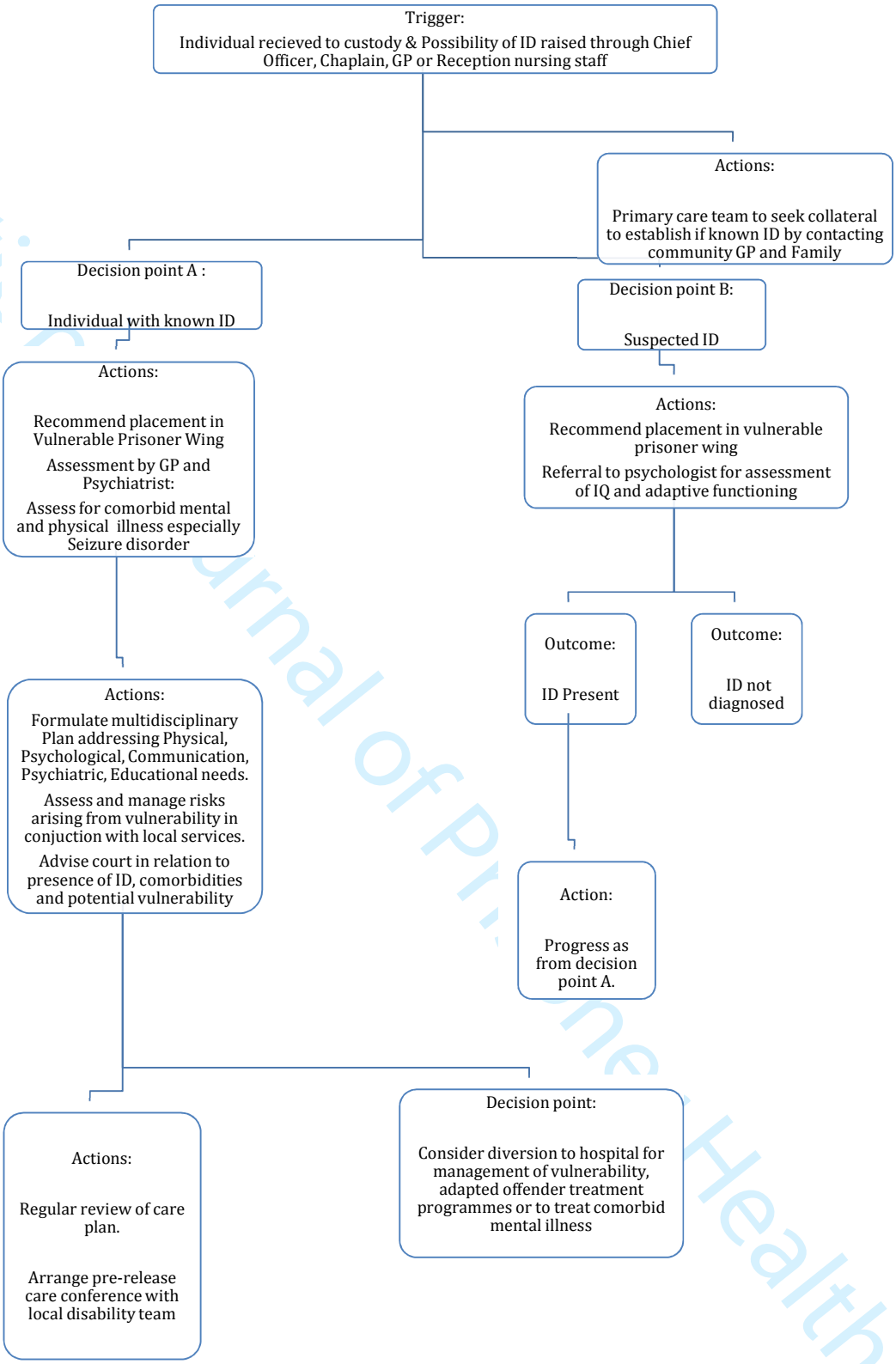
8. Which pieces of legislation do you believe are relevant to the psychiatric management of someone with an intellectual disability in a prison setting?

9. What resources have you found helpful when providing assessment and care for individuals with an ID in a prison setting? (*Examples may include guidance, advice from a colleague but also specific issues such as legal advice*)

10. What barriers have you encountered to assessing or providing care to an individual with an ID in a prison setting? What was the impact? Did you attempt to overcome them? What did you do? Did it work?

11. What changes, in your opinion, could be made to improve the assessment and care of individuals with ID in the Irish prison system?

Figure 1: A proposed care pathway for a person with ID presenting to Prison



Results

Content Analysis

The following key themes and associated content emerged from content analysis of 10 questionnaires received (n=10/12, response rate 83.3%). These were amalgamated into a proposed algorithm as presented in **Figure 1**, and agreed by participants.

Assessment

Participants in our study reported that individuals with ID may be identified by prison staff or the judge/legal team in Court when issues arise in relation to fitness to stand trial. However, those with mild ID / borderline ID may not be identified as frequently.

The Chief Officer (the most senior prison officer) would have a key role in identifying vulnerable prisoners and requesting assessments to be conducted. The prison chaplain can often help identify vulnerable individuals in prisons. Subsequent assessment would be directed by whether there is an existing diagnosis of ID, and collateral from community services and family would assist in this. A formal case conference with local disability services would inform assessment and management where someone is already known to have ID.

A psychiatric history and mental state examination should be appended with questions around vulnerabilities such as bullying, financial exploitation, sexual exploitation, homelessness, harmful behaviour such as sharing needles where injection drug misuse

is comorbid and risks to others such as violence (e.g. to elderly parents) and inappropriate sexual behavior, based on the nature of the offences. Medical history was highlighted as important, as higher rates of seizure disorders which of themselves may require special observation/placement in vulnerable prisoners wing. Formal IQ testing will often, but not always, have been done in the community. This may need to be completed by the psychologist based at the prison, alongside assessment of adaptive functioning using standardised assessments. Participants reported that neuropsychological evaluations are more difficult to access and the court may be asked to order this from the independent sector (professionals working in independent organisations on a case by case basis). Behavioural analysis where required may also involve specialist assistance. Assessments may include fitness to stand trial, determination of ability to cope in the prison environment alongside rehabilitation needs and identification of any comorbidities, such as mental illness and neurodevelopmental disorder.

Management

Care provision

Participants identified that the current care available to those with ID in the prison setting was variable in multidisciplinary membership, usually only comprising a doctor and nurse. Participants highlighted the need for multidisciplinary care availability for individuals with ID involving Psychiatrists, Psychologists, Social Workers, Occupational Therapy, Speech and Language Therapy, a General Practitioner and educational staff mirroring the hospital-based service in Dublin. In

particular, the lack of availability of adapted courses such as 'stress management' and 'effective communication' was identified as a need, as well as the lack of a 'Prison Welfare Officer' who historically performed a valuable role with vulnerable prisoners. On the other hand, it was felt "difficult to identify supports appropriate to someone who presented a with potentially highly criminalised lifestyle and low intellectual functioning".

Diversion to hospital

Participants identified that transfer to hospital may be needed in a number of different circumstances:

a) When the person with ID is, as a consequence of their ID, vulnerable to harm in the prison setting.
b) In relation to issues arising from unfitness to stand trial.
c) When the person with ID has a mental illness which cannot be safely or effectively treated in prison.
d) When the person with ID cannot, as a result of the ID, engage effectively with a rehabilitation and education programme that would be necessary to reduce the risk of re-offending, transfer to a specialist in-patient unit can provide adapted offender treatment programmes.

Although the Criminal Law (Insanity) Act, 2006 has provisions for the transfer of prisoners to a hospital setting, lack of specialist inpatient hospital beds was seen as a barrier to effective provision of diversion, as was perceived reticence from community services to accept a prisoner based on stigma conferred by this status. This was more often the case for people with mild or borderline ID, specialist services

for whom are still in early development in Ireland despite the fact that these were recommended a decade ago (Department of Health & Children, 2006).

Recommendations

Participants raised the potential value of screening to identify people with ID registered on the National Intellectual Disability Database on reception to prison, in order to mobilise additional monitoring and/or support to reduce the "risk of harm, exploitation or even radicalization".

Awareness training for prison staff on induction as well as for members of the judiciary and probation services were seen as potentially impacting the care pathway for those with ID. The need for advocacy, often through close liaison with the individual's solicitor, was outlined as a measure to ensure equitable rights for people with ID.

Simple interventions such as a "communication passport" may help improve quality of life and help navigate the legal system. There is a need for multidisciplinary input with general practitioners, psychologists, psychiatrists, nursing staff, specially trained welfare officers, chaplains and educational staff. The latter may assist with adapted courses such as those addressing "effective communication" and "stress control".

Advice from local disability teams (i.e. from person's home area) and their attendance at case conference was seen as important in helping inform care in prison and in pre-release planning. The development of care pathways through expansion in the

provision of specialist hospital beds and funding for specialist community placements was identified.

Vulnerability

Participants identified vulnerability as a major concern for those with ID in prisons. Bullying may relate to attempts to acquire their medication, persuade them to use illicit drugs, and could extend to emotional, financial and sexual exploitation. Particular challenges were highlighted in the management of persons with autistic-spectrum disorders, who not infrequently present following violent offences but are more likely to be victims of violence in prison settings. Placement on vulnerable prisoner wings were seen as an important measure to help manage some of these difficulties.

Conclusions & Discussion

This study proposes a care pathway for the assessment and management of prisoners with an intellectual disability based on expert elicitation and consensus. This is a subject where there is relatively little structured guidance to date. Although written from an Irish perspective, it outlines key considerations in keeping with international principles (UNODC, 2009; World Health Organisation, 2008) and, therefore, may be generalisable to similar jurisdictions. Care considerations proposed in Australia (State of Victoria, 2008) specific to legal, probation and governmental provisions in the State of Victoria highlight parallel overarching considerations as proposed in our algorithm.

A particular strength of our study is the involvement of representatives from multiple disciplines and an expert external to the jurisdiction. Use of the Delphi method lends to external validity by coalescing the views of multiple experts (Hasson et al, 2000). Our response rate for each round exceeded the suggested response rate of 70% for this method (Sumsion, 1998). A limitation of our study is that the overall number of experts involved is small, as would be expected in a relatively small jurisdiction. Additionally, to pursue non-respondents, the identity of the participants was known to the primary researcher and therefore the process was `quasi-anonymous' (McKenna, 1994).

Participants in this study stressed the need for equivalence of care for those with ID such that it mirrors provision in the community. This is in keeping with European and international principles for the provision of prison healthcare (United Nations General Assembly, 1990; World Health Organisation, 2008; Council of Europe, 1998; CPT, 2002).

However, responses to our initial survey showed that current care is limited and geographically disparate within Irish prisons. This is similar to the situation in other jurisdictions such as the US (Wilper et al., 2009) and the UK (Offender Health Research Network, 2009). A lack of standardised care for those with ID was highlighted in the UK by the prison inspectorate (Wilson & Hardwick, 2015) who found "*extremely poor systems for identifying prisoners with learning disabilities…Even where a learning disability was identified, it was not always sufficiently taken into account in prison processes …As a result, prisoners with learning disabilities are at risk of having a much more difficult time in prison than*

those who do not". Without the appropriate resourcing of prison care services, this proposed care pathway is likely to have a limited impact in practice, and especially so in prisons where the current multidisciplinary complement is limited to a doctor and a nurse; in such prisons, the assessment of those with suspected ID poses a significant challenge. In the absence of appropriate identification, there will be a lack of access to vital services and a potential lack of safeguarding.

Whilst screening for mental illness is developing, systematic screening for intellectual disabilities does not occur currently in Irish prisons. It seems reasonable to state that this may be a focus of significant future research as such screening has been shown to be feasible in other jurisdictions (Board, Ali & Bartlett, 2015). In particular, several screening tools have been cited in relation to the screening of intellectual disabilities in prison populations (Hayes, 2002; Paxton & McKenzie, 2006). These have included the Kaufman Brief Intelligence Test (KBIT), the Vineland Adaptive Behaviour Scales (VABS), the Hayes Ability Screening Index (HASI) and the Learning Disability Screening Questionnaire (LDSQ). The LDSQ has been validated in a UK sample; arguably the most closely-related to an Irish cohort (McKenzie, Sharples & Murray, 2015). The test is a 7-item scale, does not require the assessor to have particular qualifications or training, with demonstrated discriminative validity in forensic populations (Paxton et al., 2008; McKenzie at al, 2012). It is notable, however, that none of these tools have been validated specifically in an Irish setting, and the impact of cultural and socioeconomic diversity may represent further research avenues.

Physical health comorbidity is common in people with intellectual disability (Bradshaw et al,. 2017; Lhatoo & Sander, 2001). There is, in particular, an elevated risk of seizure disorder which may be associated with higher mortality (Robertson et al., 2015) and needs specialist care planning (Murphy et al., 2017; NIHCE, 2016). Participants in our study identified that the assessment of such comorbidity is important and may necessitate specialist placement in itself. Little is known about how such physical health comorbidity is currently managed within the prison setting. In keeping with the principle of equivalence of prison healthcare, a further consideration would be an audit of physical healthcare provision for those with ID in prisons using accepted standards from the community (NIHCE, 2016).

The lack of access to specialist hospital beds for those with ID so as to facilitate diversion was further highlighted as a barrier to delivering effective care. Ireland has the lowest complement of secure beds in Western Europe (Kennedy, 2016) and to develop these would need both political will and specialist expertise.

Participants in our study highlighted the vulnerability of those with ID in the prison setting. This is in keeping with international literature (Hellenbach et al., 2017) in relation to those with ID and parallels the elevated risk of sexual and violent victimisation in the community (Fogden et al., 2016). Vulnerability may be magnified when there are comorbidities such as Autism Spectrum Disorder, which can lead to challenges arising from social naivety and sensory difficulties and “meltdowns” being perceived as challenging behavior (Murphy, 2010; Dein & Woodbury-Smith, 2009). Placement on vulnerable prisoner wings may mitigate such risks, but exposes those placed in such settings to limited social contact, a restricted prison regime and

potential stigmatization. Arguably, the answer lies in prevention, i.e. effective diversion prior to imprisonment. From an Irish perspective, the interim report of the Interdepartmental Group to examine issues relating to people with mental illness who come in contact with the criminal justice system in Ireland (Department of Justice, 2016) and A Vision for Change (Department of Health and Children, 2006) raise the importance of inter-agency working and potential diversion of those with mental illness and/or ID at the point of arrest and/or custody through the involvement of An Garda Siochana (literally 'Guardians of the Peace'; the Irish police force). However, diversion services at the arrest and police custody stage of the criminal pathway are yet to be developed in Ireland.

Within existing services, despite geographical variability, one recommendation that is achievable is the use of case conferences to facilitate care planning in prison and post-release planning (Bradshaw et al., 2017) in conjunction with local disability teams. This may be the first step in ensuring that specialist expertise is made available to a person who needs it, and that interfaces such as release associated transfer of care are not times of undue stress for people with ID. This would need strengthening of links between the state health service, voluntary sector and prison service and a coordinated approach that breaks down practical barriers at these interfaces.

The care pathway proposed in this study is not exhaustive, and is not designed to be such. It is an expert consensus view from one jurisdiction, but it raises many pertinent issues central to the care of those with ID in prisons that are generalisable. If adopted in practice, it may represent an opportunity for people with an intellectual disability in prison to have their basic rights respected (Irish College of Psychiatrists, 2005).

Having said that, the value of any proposed pathway lies in effective implementation; future research may usefully be aimed at process mapping the journeys of individuals with ID who find themselves in contact with the Criminal Justice System to learn lessons about the degree to which this pathway is being implemented at the level of the individual and wider systems.

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